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The Canadian Survey of Health, Lifestyle and Aging with Multiple Sclerosis; Methodology and Initial Results

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1

Short Title: Health Lifestyle and Aging with Multiple Sclerosis

Tables: 3
Figures: 2

2

ABSTRACT

Objective
People with multiple sclerosis (MS) are living longer so strategies to enhance long term health and quality of life are garnering more interest. We aimed to create a profile of aging with MS in Canada focusing on health and lifestyle factors, disability, participation and quality of life in order to determine factors associated with healthy aging.

Design
National multi-centre postal survey

Setting
Recruitment from Canadian MS clinics, MS Society of Canada chapters, and newspaper advertisements

Participants
People aged 55 years or older with MS symptoms more than 20 years

Outcome Measures
Validated outcome measures and custom-designed questions examining MS disease characteristics, living situation, disability, co-morbid conditions, fatigue, health behaviours, mental health, social support, impact of MS, and others.

Results
Of the 921 surveys, 743 were returned (80.7% response rate). Participants (mean age 64.6 ±6.2 years) reported living with MS symptoms for an average of 32.9±9.5 years and 28.6% were either wheelchair users or bedridden. There was only 5.4% missing data and 709 respondents provided optional qualitative information. According to data derived from the 2012 Canadian Community Health Survey of Canadians over 55 years of age, older people with MS from this survey sample are about 8 times less likely to be employed full-time. Older people with MS were less likely to engage in regular physical activity (26.7%) compared to typical older Canadians (45.2%). However, they were more likely to abstain from alcohol and smoking.

Conclusion
Despite barriers to participation, we were able to recruit and gather detailed responses (with good data quality) from a large proportion of older Canadians with MS. The data suggests that this sample of older people with MS are less likely to be employed, are less active and more disabled than other older Canadians.

3

Strengths and limitations of this study

- This unique cohort provides new insights on aging with MS. With an average age about 65 years, our respondents are 10 to 25 years older than cohorts examined in previous studies of older people with MS.

- Our recruitment methods and a very high survey return rate allowed us to obtain data from about 3% of our target population.

- With only about 10% of our sample being employed in any capacity, our results point to a need to understand retirement and employment in aging with MS.

- The cross sectional design limits our ability to assess change and the effects of variables on individual outcomes over time.

- The low sampling of persons in nursing homes and assisted living situations highlights the need for specialized recruitment strategies to study this sub-set of people living with MS.

4

INTRODUCTION

Multiple Sclerosis (MS) is a highly unpredictable and heterogeneous autoimmune disease diagnosed between the ages of 18-40 years. Affecting women more than men, the cause of MS is unknown, however research suggests that a combination of environmental factors and genetic predisposition may be the trigger for disease onset [1]. The number of people with MS over the age of 55 is increasing, possibly due to improved longevity and more effective treatments [2]. On the other hand, several authors have shown that smoking [3] and cardiovascular disease [4] accelerate disease progression. People with MS are interested in strategies that minimize disability and enhance role participation and quality of life [5]. The uncertainty surrounding MS progression along with aging MS patients warrants the need for investigation into potential disease modifying health behaviours. Older individuals who have lived with MS for many years may provide insight into factors that contribute to living a long and healthy life with MS [6].

Older people with MS are often excluded from MS research. Studies involving clinical drug trials [7] and exercise interventions [8], in particular, target patients with mild relapsing-remitting disease. Furthermore, because they may not require intensive medical oversight associated with taking disease-modifying drugs, older patients may not attend MS clinics as often as those recently diagnosed. The older MS cohort are also more likely to be disabled and living in an institutional setting, making recruitment challenging. In addition, disability-related impairments such as those affecting vision, cognition and coordination complicate survey and patient-reported outcome administration [9].

In order to create a profile of aging with MS in Canada, we developed a national cross-sectional survey, based on previous qualitative research [5 6], using validated patient-reported outcome measures [9]. We focused on health and lifestyle factors, disability, participation and quality of life, targeting people 55 years of age and older with MS symptoms for 20 or more years. By partnering with major MS clinic registries and MS society chapters, we hypothesized that we would be able to reach a representative sample of about 5% of the 'aging with MS in Canada' cohort.

METHODS

Participants and Sampling: We targeted Canadians, aged 55 years or older, who had had self-reported MS symptoms for 20 or more years. Prior to recruitment, the study was approved by 11 health research ethics boards in eight Canadian provinces. Between May 2011 and December 2012, participants were recruited by telephone from lists of eligible MS clinic patients and by public advertising through the MS Society of Canada Research Internet Portal[10], local MS Society chapters and their newsletters, and newspaper advertisements. A confirmed diagnosis from a neurologist was available for participants recruited through the MS clinic databases; self-identified participants provided a diagnosis date and neurologist name to confirm their diagnosis. Rather than calculating a sample size, we used an exhaustive sampling technique to obtain a large and representative sample; for example repeatedly targeting regional newspapers, following-up at study sites, making formal and informal contacts with MS Society Chapter support groups.

After obtaining consent using a standard script, we mailed participants the questionnaire, with an information sheet, a toll-free telephone helpline number and email address and a prepaid

6

reply envelope. We requested that participants return the completed survey in 2 weeks; non-responders were telephoned for follow-up at 4 weeks. Participants who wished to complete the survey by telephone were encouraged to do so. Each questionnaire was coded to maintain anonymity.

Survey Design: The questionnaire consisted of validated patient-reported outcome tools and additional custom-designed questions chosen based on pilot research in a small sample of older people with MS [9]. Based on pilot work and participant feedback, a (paper) mail version of the survey using a larger 14-point font was divided into sections that grouped similar questions together. Respondents were instructed to complete the survey in these sections (chapters) taking a break in between. Since we previously observed confusion with questions involving temporal parameters, questions regarding activity involvement that followed the same timeline (e.g. weekly, monthly, or yearly) were placed in sequence. To further examine the acceptability of the survey and to minimize skipped or misunderstood items, we asked the first 14 participants (11 returns) to provide feedback on the content, format and response burden. This feedback was integrated into the final version of the questionnaire but the responses were not included in the final data.

In order to include people with MS in the province of Quebec, Canada, the entire survey including the cover letter was translated into french by one independent professional translator. We also obtained french versions of previously validated tools. Four native french speakers involved in MS research made corrections to the initial translation in sequence. The corrections where then consolidated by a fifth french speaking MS researcher. The advertisement and

7

consent scripts were translated by a native french speaking MS researcher and reviewed and

corrected by a second.

Survey Content: The final survey consisted of five chapters (**Table 1**) ending with open response

questions for participants to provide additional comments. Where appropriate, we obtained

permission from the developers to use previously validated tools.

We used the Multiple Sclerosis Impact Scale (MSIS-29), the Barthel Index and the Co-

morbidity Questionnaire to assess health. The MSIS-29 consists of 29 questions: 20 address the

physical impact and nine address the psychological impact of MS generating separate or

combined scores as a percentage of 100. Higher scores indicate greater impact of MS [11]. The

Barthel Index measures function and mobility in activities of daily living (ADL) in ten areas:

feeding, bathing, grooming, dressing, bowel control, bladder control, toileting, transfers,

ambulation and stair climbing [12]. Items are rated in terms of whether individuals can perform

activities independently, with some assistance, or are completely dependent, with a total score

ranging from 0 (complete assistance required) to 100 (independent). The Barthel Index has been

tested in people with MS [13-15] and is reliable whether administered by telephone, in-person or

by mail [16]. The list of co-morbidities used in this survey was adapted from Marrie and Horwitz

[17 18] in consultation with Dr. Marrie (personal communication).

We determined the degree of participation in instrumental activities of daily living

(iADL) using the Frenchay Activities Index (FAI) and individual components of lifestyle

(exercise, diet, smoking, alcohol, and stress) using the Simple Lifestyle Indicator Questionnaire

8

(SLIQ). The FAI assesses the frequency of participation in domestic chores, social activities, work and leisure for a summed score from 0 – 45; higher score indicating more frequent participation [19]. The FAI has excellent test-retest reliability as a mailed questionnaire [20] and correlates well with face-to-face interview scores [21]. The FAI has been mainly used in stroke but has also been used in large MS population studies [22 23]. The SLIQ was developed to measure the individual components of lifestyle that affect cardiovascular disease[24]. Initial content and face validity were assessed by the developers among 136 people attending a family practice clinic[24].

We were also interested in mental health, coping and social support in aging with MS. The Hospital Anxiety and Depression Scale (HADS) is a self-assessment scale found to reliably screen for depression and anxiety in multiple sclerosis patients [25]. It is divided into an Anxiety subscale (HADS-A) and a Depression subscale (HADS-D) each containing seven intermingled items scored out of 21; higher score indicating greater symptoms [26]. Resilience, the ability to overcome adversity, was measured using the 25 item Resilience Scale. Responses to the test questions range from 1 (disagree) to 7 (agree) and the summed score can be further interpreted as, low resilience (<120), moderate resilience (125-145), and high resilience (>145) [27] and has been validated in older community-living individuals [27]. The Personal Resource Questionnaire (PRQ-2000) measures social support and consists of 15 statements with which the subject agrees or disagrees based on a seven-point Likert scale; higher scores indicating higher support (e.g. I belong to a group in which I feel important 1-Strongly Disagree to 7-Strongly Agree). PRQ-2000 demonstrates adequate content, predictive and construct validity [28] and mailed versions have been used in community-living women with chronic health conditions[29] and adults with MS[30].

9

Table 1: Survey Content

CHAPTER	DOMAINS	MEASUREMENT TOOLS
You and Your MS (5 pages)	**Demographics**	Postal code, gender, height, weight, age, finances and education
	MS Disease Characteristics	Symptom onset, time since diagnosis, and type of MS
	Environment	Living situation, accessibility and home modifications
Your Health (6 pages)	**Health-Related Quality of Life**	Visual analogue scale of perceived health status [9] Multiple Sclerosis Impact Scale-29 [11]
	Physical Health and Disability	Barthel Index [12] Co-Morbidity Questionnaire [17]
	Health Care Services	Use and satisfaction with health care services, medications and complementary/alternative health.
Your Activities (7 pages)	**Participation and instrumental Activities of Daily Living**	Frenchay Activities index [19]; Employment and impact of fatigue
	Lifestyle	Simple Lifestyle Indicator Questionnaire (diet, exercise, stress, smoking, alcohol) [24]
Your Thoughts and Feelings (8 pages)	**Mental/ Cognitive Health**	Hospital Anxiety and Depression Scale (HADS) Resilience Scale [25] Problems with concentration and memory
Your Social Life (4 pages)	**Social Support**	Personal Resource Questionnaire-2000 [30]

Canadian comparison data: Comparative data was collected from the Canadian Community Health Survey (CCHS) 2012 version; a national cross-sectional survey that gathers information about health, social and economic status and lifestyle behaviours of the population. Data was extracted from the CCHS database using the University of Toronto Data Library Service (DLS) [31]. A CCHS sample was selected based on age (>55 years). Data was collected from CCHS questions that matched question from our survey. Outputs (ie. highest level of education, employment status) were analyzed using Survey Documentation & Analysis (SDA) software [32]. Frequency tables were created for variables of interest.

10

Data Entry: We custom designed the database application to house project data and minimize

error during data imputation. The application was constructed using Borland Delphi 2005 as the

application interface (front end) and a freeware (<5 user) version of the Advantage database

engine for the back end. To facilitate reporting and publication, an export routine was

programmed into the database to perform the following functions: Generate a pipe delimited text

file of the main database table, iterate through the application, and associated database lookup

tables, and generate an SPSS syntax file with the applicable variable and value labels. The pipe

delimited text file was imported into SPSS and an SPSS syntax file of the import was generated

for recoding. An SPSS syntax file was generated for recoding data according to the needs

outlined in the scoring tool and applied to the data and reused with each data dump. Every

analysis performed was saved as a syntax file in order to facilitate replication, documentation

and publication.

Data Cleaning and Imputation: Missing data was imputed using three techniques: (1) deductive

imputation, (2) person mean substitution, and (3) 'hot deck' imputation [33]. The deductive

technique was used to impute missing data when there was sufficient comments and answers to

related questions. If less than half of the data was missing on a section, scale, or subscale, person

mean substitution (PMS) was used. PMS takes the mean score of the particular participant on

that section, scale, or subscale and uses the mean as the value for the missing data. If greater than

half of the data was missing on a section, scale, or subscale, 'hot deck' imputation was used [33].

This involved taking a value from the "hot deck" or in other terms, finding another participant of

the same gender, age (±5 years), education level, and living in the same province. Hot deck

11

imputation was selected for this study because it is proven to be the most efficient method of

data imputation as it is more robust in large samples when compared to other imputation

methods [33]. The exact scores for each question from the substitute participant were imputed

for the missing values for the participant of interest. Variables that could not be imputed and

remained empty included, from **Table 1**, Demographics (e.g. weight, height, finances), MS

Disease Characteristics, Environment, and Health Care Services.

Data Analysis: Data was analyzed using IBM SPSS software v20. Frequencies and descriptive

statistics (mean, SD and data range) were used to determine subject characteristics.

RESULTS

Survey Response

Seven hundred and forty three participants returned the survey (**Figure 1**; 80.7%

response rate). Survey response by province is illustrated in **Figure 2**. Of the respondents, 90.4%

(n=672) were identified through provincial MS clinics while the remaining 71 self-identified by

responding to newspaper ads and word of mouth. Forty-five people requested help to complete

the survey, and 11 participants asked that the entire survey be completed by phone due to writing

or vision difficulties or both. Additional content was provided by 709 participants in the open-

ended questions at the end of the survey.

Only 563 of 104,763 cells contained missing data (5.37%). Almost every survey

contained one or two random missing items; in some cases answers to these could be inferred

using deductive reasoning (67/104,763=0.06%). We observed no pattern of missing data other

than body weight (which we did not impute). The PMS technique was required for 170 cells (170/94,763=0.16%) and the 'hot deck' technique was required in 14 surveys (324 cells/104,763=0.31%). Cases of consecutive missing data seemed to be mainly due to pages adhering together resulting in questions being overlooked.

Insert Figure 1 about here

Sample Characteristics

Participants ranged in age from 55 to 88 years with a mean age of 64.6 years (±6.18). They described experiencing MS symptoms for 20 to 73 years with a mean duration of 32.9 years (±9.5). The respondents reported that the average time from onset of symptoms to diagnosis by a neurologist was 8.05 years (± 9.39) with a range from 0 to 47 years. The number of women outnumbered men 3.48:1 (**Table 2**).

Sixty percent reported at least one year of post-secondary education, and 90% were either retired or unemployed. About twenty-eight percent of the sample (n=212) reported that they were no longer able to walk and either used a wheelchair or were bedridden. The characteristics of the sample are fully described in **Table 2**.

13

Table 2: Sample Characteristics

Characteristic		N (%)
Gender	Males	166 (22.3)
	Females	577 (77.7)
Age	55-64	414 (55.7)
	65-74	274 (36.9)
	75-84	50 (6.7)
	85+	5 (0.7)
Years with MS Symptoms	20-29	324 (43.6)
	30-39	245 (33.0)
	40-49	135 (18.2)
	50-59	31 (4.2)
	60 or more	7 (0.9)
Initial MS Diagnosis	Relapsing-Remitting	386 (52.0)
	Primary Progressive	99 (13.3)
	Secondary Progressive	65 (8.7)
	Progressive-Relapsing	16 (2.2)
	Benign	43 (5.8)
	Unknown	126 (17.0)
Living situation	Living in a private home	715 (96.2)
	Living in an assisted living complex	16 (2.2)
	Living in long term care	11 (1.5)
	Home Care	146 (19.7)
	Equipment	200 (26.9)

	Home Modifications	73 (9.8)
Private Insurance (Health/Disability)	Yes	393 (52.9)
	No	350 (47.1)

Insert Figure 2 about here

Older people with MS compared to typical older Canadians

According to data derived from the 2012 Canadian Community Health Survey (CCHS; **Table 3**) of Canadians over 55 years of age, older people with MS from this survey sample have less post-secondary education and are about 8 times less likely to be employed full-time. About half of the survey sample have major mobility challenges (unable to walk outdoors, use a wheelchair or are bedridden) compared to only 9% in the CCHS sample. Not surprising, older people with MS were less likely to engage in regular physical activity (26.7%) compared to typical older Canadians (45.2%). However, they were more likely to abstain from alcohol and smoking.

Table 3: Comparison of Sample Characteristics to Others Aging in Canada

Characteristic		Study sample (%)	CCHS sample (%)
Education	Less than high school	74 (10.0)	1,241,946 (15.2)
	High School	222 (29.9)	1,083,618 (13.3)
	1-2 year post-secondary	189 (25.4)	4,088,252 (4.9)
	Complete Post-graduate	258 (34.7)	5,442,586 (66.6)
Employment	Retired	504 (67.8)	2,878,200 (46.3)

15

Status	Unemployed	166 (22.3)	302,942 (4.8)
	Employed Full-time	30 (4.0)	2,068,571 (33.3)
	Employed Part-time	19 (2.6)	698,125 (11.2)
	Employed Casual	24 (3.2)	266,419 (4.3)
Mobility	Walk independently with or without cane outdoors	351 (47.2)	8,004,425 (90.9)
	Walk with cane or help indoors	180 (24.2)	593,584 (6.7)
	Wheelchair	161 (21.7)	
	Unable to move	51 (6.9)	204,744 (2.3)
Lifestyle	Moderate to Vigorous Exercise	374 (50.3)	1,764,305 (20.7)
	Some physical activity	252 (33.9)	2,083,695 (24.5)
	No physical activity	117 (15.7)	4,652,856 (54.7)
	No alcohol use	385 (51.8)	2,226,486 (26.3)
	14 or less drinks per week	344 (46.3)	1,242,238 (14.6)
	>14 drinks per week	14 (1.9)	5,009,245 (59)
	Non-Smokers		7,422,711 (84.4)
	Never smoked	272 (36.6)	
	Quit	404 (54.4)	
	Smokers	67 (9.0)	1,372,885 (15.6)

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DISCUSSION

The purpose of this national cross-sectional survey was to describe aging with MS in

Canada that would provide the data necessary to determine, in future analysis, the influence of

personal, health and environmental factors on quality of life and disability among older people

with MS. Incidence and prevalence estimates of MS in Canada are amongst the highest

worldwide [34] and a shift in peak age prevalence of MS to older ages suggesting that persons

with MS in Canada are living longer [2]. Interventions to promote successful aging with MS may

take on more importance over the next decade since quality-of-life and productivity in advanced

age is a desired outcome for most [6]. To our knowledge this is the most comprehensive study

focusing on examination of health and lifestyle factors specifically among older persons with

MS.

The prevalence of MS in Canada has been estimated to be 240 per 100,000 [34]. The

CCHS estimates that there are 93,535 Canadians living with MS [31] and since Statistics Canada

estimates that people over 55 make up about 27.7% of the population [35], there could be

approximately 25,000 people with MS over 55 years of age. We attempted to contact as many

older people with MS as possible and our sample (n=743) likely represents about 3% of this

group, less than our initial 5% target. Data quality was very good with only 5.4% missing data

and 709 respondents providing optional qualitative data. The high rates of response and

completion and may be due to pre-screening of potential respondents at clinic sites. Only 7.5%

of respondents required assistance by the research team but we were unable to discern survey

completion by proxy.

With an average age about 65 years, our respondents are 10 to 25 years older than cohorts

examined in previous studies of older people with MS [36-42]. Compared to these previous

17

studies, which reported the number of years since MS diagnosis ranging from 8-19 years [37 38], our participants have been diagnosed with MS for 24.8 (±10.0) years. Our respondents' level of education aligns with most other studies of people with MS [37-39 41] .The group is fairly well-educated which is not surprising considering characteristics of people who respond to surveys in general [43]. When compared to the Canadian population [31], fewer of our respondents had advanced education including post-secondary degrees and post-graduate degrees. Furthermore, only about 10% of our sample was employed in any capacity which is substantially lower than other studies of older people with MS [36 38 41]. Since maintaining employment is associated with better quality-of-life, at least in younger people with MS [41], factors associated with employment and retirement as one ages with MS will be an important area of future study.

More than a quarter of our cohort were severely disabled (28.6%); over ten times that of aging counterparts in Canada (2.3%). They either were restricted to ambulation with a wheelchair or walking with physical assistance indoors or were bedridden; an interesting finding given that most respondents lived in private residences (96.2%) without home care, equipment or home modifications. Since only about half of respondents had private health insurance, it is possible that most people manage at home with few resources outside of the publicly-funded health system and the care provided by spouses and children. Since the proportion of respondents living in assisted-living and long-term care in this study was small, our sample may not be representative of older people with MS living in these settings.

In terms of lifestyle behaviours, the participants in this study were less physically active but less likely to drink alcohol or smoke compared to their Canadian counterparts [31]. In large cohorts of people with MS in the United Kingdom (n=895) and Belgium (n=1372), healthy lifestyle behaviours are associated with less severe and less rapid disability progression [44 45].

18

Poor lifestyle behaviors, specifically smoking, have been associated with increased risk of

comorbid diseases [46]. Future studies will examine the role of health behaviors and disability in

this group of older people with MS.

Although this unique cohort may provide new insights on aging with MS, there are some

study limitations. The cross sectional design limits our ability to assess change and the effects of

variables on individual outcomes over time. By nature of the volunteer survey design, our sample

may be biased in that active participants were more likely to respond. Even though we provided

assistance over the phone, those with significant disability who required assistance may have

declined. The low sampling of persons in nursing homes and assisted living situations highlights

the need for specialized recruitment strategies to study this sub-set of people living with MS.

Conclusion

Despite barriers to participation, we were able to recruit and gather detailed responses

(with good data quality) from a large proportion of older Canadians with MS. Even with

extensive pretesting, national collaboration, exhaustive sampling and high return rates, our

recruitment (n=743) was less than our target (n=1250). However, we were able to recruit a large

proportion of people who were severely disabled even though only 7.5% of respondents

requested assistance. The data suggests that this sample of older people with MS are less likely

to be employed, are less active and more disabled than other older Canadians.

19

Contributorship

Concept development and funding applications- MP, JDF, MG
Ethics applications and participant recruitment-MP, CH, OJM, SH, JDF, ADS, PO, SAM, LMM,
KK, PS, NM, RAM, MS
Data collection, management and analysis-MP, OJM, SB, CH, SH, PWA
Manuscript preparation and /or review-MP, OJM, CH, JDF, ADS, PO, SAM, LMM, PS, NM,
RAM, MS, MG

Data sharing

Analysis on this study data is ongoing. Currently six additional unpublished manuscripts are in
preparation.

Competing Interests

None

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21

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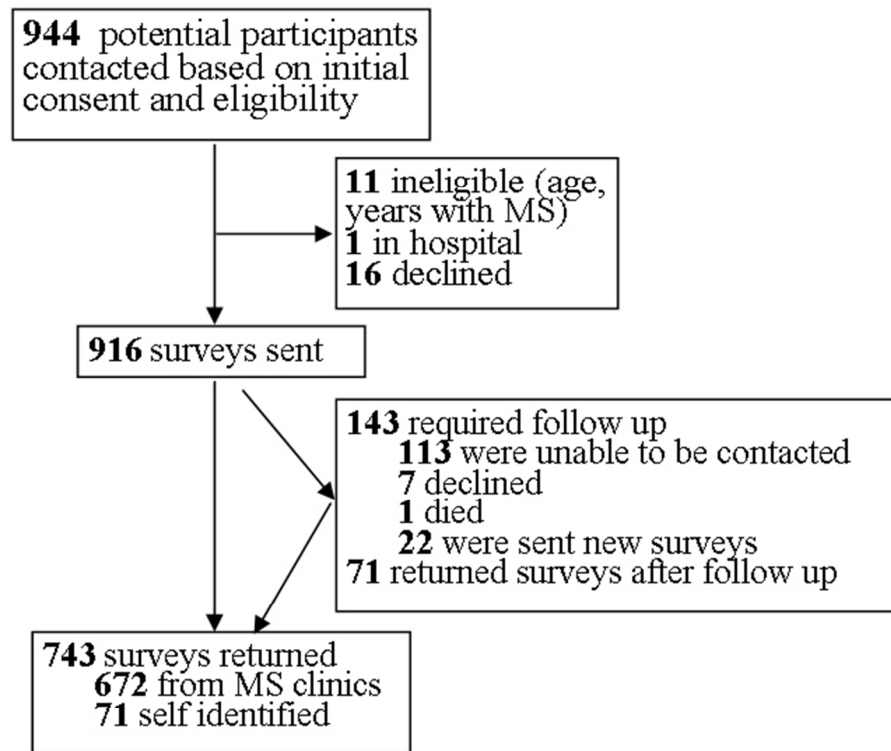
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Figure 1: Survey Respondents
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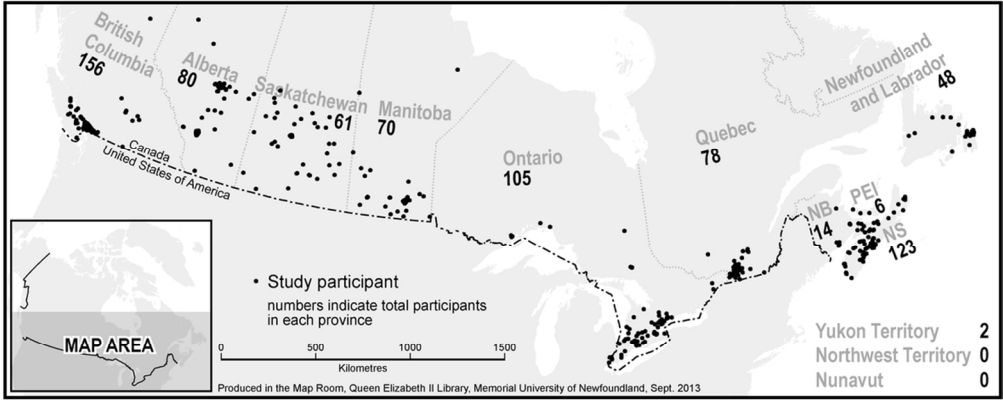49
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Figure 2: Number of respondents mapped by postal code
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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Complete
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	✓
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	✓
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	✓
Objectives	3	State specific objectives, including any prespecified hypotheses	✓
Methods			
Study design	4	Present key elements of study design early in the paper	✓
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	✓
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls	
		Cross-sectional study—Give the eligibility criteria, and the sources and methods of selection of participants	✓
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	✓
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	✓
Bias	9	Describe any efforts to address potential sources of bias	✓
Study size	10	Explain how the study size was arrived at	✓
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	✓
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	✓
		(*b*) Describe any methods used to examine subgroups and interactions	✓
		(*c*) Explain how missing data were addressed	✓
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	✓
		(*e*) Describe any sensitivity analyses	✓

Results

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	✓
		(b) Give reasons for non-participation at each stage	✓
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	✓
		(b) Indicate number of participants with missing data for each variable of interest	✓
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	✓
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	✓
		(*b*) Report category boundaries when continuous variables were categorized	✓
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	✓
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	✓

Discussion

Key results	18	Summarise key results with reference to study objectives	✓
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	✓
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	✓
Generalisability	21	Discuss the generalisability (external validity) of the study results	✓

Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	✓

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

The Canadian Survey of Health, Lifestyle and Aging with Multiple Sclerosis; Methodology and Initial Results

The Canadian Survey of Health, Lifestyle and Aging with Multiple Sclerosis; Methodology and Initial Results

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1

Short Title: Health Lifestyle and Aging with Multiple Sclerosis

Tables: 3
Figures: 4

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ABSTRACT

Objective
People with multiple sclerosis (MS) are living longer so strategies to enhance long term health and quality of life are garnering more interest. We aimed to create a profile of aging with MS in Canada by recruiting 1250 (5% of the Canadian population over 55 with MS) participants and focusing data collection on health and lifestyle factors, disability, participation and quality of life in order to determine factors associated with healthy aging.

Design
National multi-centre postal survey

Setting
Recruitment from Canadian MS clinics, MS Society of Canada chapters, and newspaper advertisements

Participants
People aged 55 years or older with MS symptoms more than 20 years

Outcome Measures
Validated outcome measures and custom-designed questions examining MS disease characteristics, living situation, disability, co-morbid conditions, fatigue, health behaviours, mental health, social support, impact of MS, and others.

Results
Of the 921 surveys, 743 were returned (80.7% response rate). Participants (mean age 64.6 ±6.2 years) reported living with MS symptoms for an average of 32.9±9.5 years and 28.6% were either wheelchair users or bedridden. There was only 5.4% missing data and 709 respondents provided optional qualitative information. According to data derived from the 2012 Canadian Community Health Survey of Canadians over 55 years of age, older people with MS from this survey sample are about 8 times less likely to be employed full-time. Older people with MS were less likely to engage in regular physical activity (26.7%) compared to typical older Canadians (45.2%). However, they were more likely to abstain from alcohol and smoking.

Conclusion
Despite barriers to participation, we were able to recruit and gather detailed responses (with good data quality) from a large proportion of older Canadians with MS. The data suggests that this sample of older people with MS are less likely to be employed, are less active and more disabled than other older Canadians.

3

Strengths and limitations of this study

- This unique cohort provides new insights on aging with MS. With an average age about 65 years, our respondents are 10 to 25 years older than cohorts examined in previous studies of older people with MS.

- Our recruitment methods and a very high survey return rate allowed us to obtain data from about 3% of our target population.

- With only about 10% of our sample being employed in any capacity, our results point to a need to understand retirement and employment in aging with MS.

- The cross sectional design limits our ability to assess change and the effects of variables on individual outcomes over time.

- The low sampling of persons in nursing homes and assisted living situations highlights the need for specialized recruitment strategies to study this sub-set of people living with MS.

4

INTRODUCTION

Multiple Sclerosis (MS) is a highly unpredictable and heterogeneous autoimmune disease diagnosed between the ages of 18-40 years. Affecting women more than men, the cause of MS is unknown, however research suggests that a combination of environmental factors and genetic predisposition may be the trigger for disease onset [1]. The number of people with MS over the age of 55 is increasing, possibly due to improved longevity and more effective treatments [2]. On the other hand, several authors have shown that smoking [3] and cardiovascular disease [4] accelerate disease progression. People with MS are interested in strategies that minimize disability and enhance role participation and quality of life [5]. The uncertainty surrounding MS progression along with aging MS patients warrants the need for investigation into potential disease modifying health behaviours. Older individuals who have lived with MS for many years may provide insight into factors that contribute to living a long and healthy life with MS [6].

Older people with MS are often excluded from MS research. Studies involving clinical drug trials [7] and exercise interventions [8], in particular, target patients with mild relapsing-remitting disease. Furthermore, because they may not require intensive medical oversight associated with taking disease-modifying drugs, older patients may not attend MS clinics as often as those recently diagnosed. The older MS cohort are also more likely to be disabled and living in an institutional setting, making recruitment challenging. In addition, disability-related impairments such as those affecting vision, cognition and coordination complicate survey and patient-reported outcome administration [9].

5

In order to create a profile of aging with MS in Canada, we developed a national cross-sectional survey, based on previous qualitative research [5 6], using validated patient-reported outcome measures [9]. We focused on health and lifestyle factors, disability, participation and quality of life, targeting people 55 years of age and older with MS symptoms for 20 or more years. By partnering with major MS clinic registries and MS society chapters, we hypothesized that we would be able to reach a representative sample of about 5% of the 'aging with MS in Canada' cohort.

METHODS

Participants and Sampling: We targeted Canadians, aged 55 years or older, who had had self-reported MS symptoms for 20 or more years. Prior to recruitment, the study was approved by 11 health research ethics boards in eight Canadian provinces. Between May 2011 and December 2012, participants were recruited by telephone from lists of eligible MS clinic patients and by public advertising through the MS Society of Canada Research Internet Portal [10], local MS Society chapters and their newsletters, and newspaper advertisements. A confirmed diagnosis from a neurologist was available for participants recruited through the MS clinic databases; self-identified participants provided a diagnosis date and neurologist name to confirm their diagnosis. Rather than calculating a sample size, we used an exhaustive sampling technique to obtain a large and representative sample; for example repeatedly targeting regional newspapers, following-up at study sites, making formal and informal contacts with MS Society Chapter support groups.

After obtaining consent using a standard script, we mailed participants the questionnaire, with an information sheet, a toll-free telephone helpline number and email address and a prepaid

6

reply envelope. We requested that participants return the completed survey in 2 weeks; non-responders were telephoned for follow-up at 4 weeks. Participants who wished to complete the survey by telephone were encouraged to do so. Each questionnaire was coded to maintain anonymity.

Survey Design: The questionnaire consisted of validated patient-reported outcome tools and additional custom-designed questions chosen based on pilot research in a small sample of older people with MS [9]. We determined during this step that participants preferred a paper rather than online version of the survey as well as larger 14-point font, divided into sections that grouped similar questions together. Respondents were instructed to complete the survey in these sections (chapters) taking a break in between. Since we previously observed confusion with questions involving temporal parameters, questions regarding activity involvement that followed the same timeline (e.g. weekly, monthly, or yearly) were placed in sequence. To further examine the acceptability of the survey and to minimize skipped or misunderstood items, we asked the first 14 participants (11 returns) to provide feedback on the content, format and response burden. This feedback was integrated into the final version of the questionnaire but the responses were not included in the final data.

In order to include people with MS in the province of Quebec, Canada, the entire survey including the cover letter was translated into french by one independent professional translator. We also obtained french versions of previously validated tools. Four native french speakers involved in MS research made corrections to the initial translation in sequence. The corrections where then consolidated by a fifth french speaking MS researcher. The advertisement and

7

consent scripts were translated by a native french speaking MS researcher and reviewed and

corrected by a second.

Survey Content: The final survey consisted of five chapters (**Table 1**) ending with open response

questions for participants to provide additional comments. Where appropriate, we obtained

permission from the developers to use previously validated tools.

We used the Multiple Sclerosis Impact Scale (MSIS-29), the Barthel Index and the Co-

morbidity Questionnaire to assess health. The MSIS-29 consists of 29 questions: 20 address the

physical impact and nine address the psychological impact of MS generating separate or

combined scores as a percentage of 100. Higher scores indicate greater impact of MS [11]. The

MSIS-29 physical component correlates with the Barthel Index (0.71) and the psychological

component with EQ-5D (0.68). It is reported to have good responsiveness with large to moderate

effect sizes [12]. The Barthel Index measures function and mobility in activities of daily living

(ADL) in ten areas: feeding, bathing, grooming, dressing, bowel control, bladder control,

toileting, transfers, ambulation and stair climbing [13]. Items are rated in terms of whether

individuals can perform activities independently, with some assistance, or are completely

dependent, with a total score ranging from 0 (complete assistance required) to 100 (independent).

The Barthel Index has been tested in people with MS [14-16] and is reliable whether

administered by telephone, in-person or by mail [17] with effect sizes comparable to the

Functional Independence Measure (0.34) [18]. The list of co-morbidities used in this survey was

adapted from Marrie and Horwitz [19 20] in consultation with Dr. Marrie (personal

communication).

We determined the degree of participation in instrumental activities of daily living (iADL) using the Frenchay Activities Index (FAI) and individual components of lifestyle (exercise, diet, smoking, alcohol, and stress) using the Simple Lifestyle Indicator Questionnaire (SLIQ). The FAI assesses the frequency of participation in household chores, social activities, work and leisure for a summed raw score of 15 to 60; higher score indicating more frequent participation [21]. The FAI has excellent test-retest reliability as a mailed questionnaire (0.96) [22] and correlates well with face-to-face interview scores [23]. The FAI has been mainly used in stroke but has also been used in large MS population studies [24 25]. The SLIQ was developed to measure the individual components of lifestyle that affect cardiovascular disease [26]. Initial content and face validity were assessed by the developers among 136 people attending a family practice clinic[26] and SLIQ scores were highly correlated with those of blinded reviewers (0.77). We were also interested in mental health, coping and social support in aging with MS. The Hospital Anxiety and Depression Scale (HADS) is a self-assessment scale found to reliably screen for depression and anxiety in multiple sclerosis patients [27]. It is divided into an Anxiety subscale (HADS-A) and a Depression subscale (HADS-D) each containing seven intermingled items scored out of 21; higher score indicating greater symptoms [28]. A threshold score of 8 or higher on HADS subscales had high sensitivity (Depression 90%, Anxiety 88.5%) and specificity (Depression 87.3%, Anxiety 80.7%) compared to structured interview using DSM-1 criteria among people with MS [27]. Resilience, the ability to overcome adversity, was measured using the 25 item Resilience Scale. Responses to the test questions range from 1 (disagree) to 7 (agree) and the summed score can be further interpreted as, low resilience (<120), moderate resilience (125-145), and high resilience (>145) [29] and has been validated in older community-

9

living individuals with high internal consistency reliability (0.91)[29] . The Personal Resource

Questionnaire (PRQ-2000) measures social support and consists of 15 statements with which the

subject agrees or disagrees based on a seven-point Likert scale; higher scores indicating higher

support (e.g. I belong to a group in which I feel important 1-Strongly Disagree to 7-Strongly

Agree). PRQ-2000 demonstrates good internal consistency (0.87 to 0.93), adequate construct

validity (moderate correlations with anxiety -0.37, neuroticism -0.28 and extroversion 0.32) and

good predictive and construct validity in multiple chronic disease data sets [30]. Mailed versions

have been used in community-living women with chronic health conditions [31] and adults with

MS [32].

Table 1: Survey Content

CHAPTER	DOMAINS	MEASUREMENT TOOLS
You and Your MS (5 pages)	**Demographics**	Postal code, gender, height, weight, age, finances and education
	MS Disease Characteristics	Symptom onset, time since diagnosis, and type of MS
	Environment	Living situation, accessibility and home modifications
Your Health (6 pages)	**Health-Related Quality of Life**	Visual analogue scale of perceived health status [9] Multiple Sclerosis Impact Scale-29 [11]
	Physical Health and Disability	Barthel Index [12] Co-Morbidity Questionnaire [17]
	Health Care Services	Use and satisfaction with health care services, medications and complementary/alternative health.
Your Activities (7 pages)	**Participation and instrumental Activities of Daily Living**	Frenchay Activities index [19]; Employment and impact of fatigue
	Lifestyle	Simple Lifestyle Indicator Questionnaire (diet, exercise, stress, smoking, alcohol) [24]
Your Thoughts and Feelings (8 pages)	**Mental/ Cognitive Health**	Hospital Anxiety and Depression Scale (HADS) Resilience Scale [25] Problems with concentration and memory
Your Social Life (4 pages)	**Social Support**	Personal Resource Questionnaire-2000 [30]

Canadian comparison data: Comparative data was collected from the Canadian Community

Health Survey (CCHS) 2012 version; a national cross-sectional survey that gathers information

about health, social and economic status and lifestyle behaviours of the population. Data was

extracted from the CCHS database using the University of Toronto Data Library Service (DLS)

[33]. A CCHS sample was selected based on age (>55 years). Data was collected from CCHS

questions that matched question from our survey (e.g. mobility from the Barthel Index and

lifestyle from the SLIQ). Outputs (ie. highest level of education, employment status) were

analyzed using Survey Documentation & Analysis (SDA) software [34]. Frequency tables were

created for variables of interest.

Data Cleaning and Imputation: We custom designed the database application to house project

data and minimize error during data imputation. Missing data was imputed using three

techniques: (1) deductive imputation, (2) person mean substitution, and (3) 'hot deck' imputation

[35]. The deductive technique was used to impute missing data when there was sufficient

comments and answers to related questions. If less than half of the data was missing on a section,

scale, or subscale, person mean substitution (PMS) was used. PMS takes the mean score of the

particular participant on that section, scale, or subscale and uses the mean as the value for the

missing data. If greater than half of the data was missing on a section, scale, or subscale, 'hot

deck' imputation was used [35]. This involved taking a value from the "hot deck" or in other

terms, finding another participant of the same gender, age (±5 years), education level, and living

in the same province. Hot deck imputation was selected for this study because it is proven to be

the most efficient method of data imputation as it is more robust in large samples when

11

compared to other imputation methods [35]. The exact scores for each question from the

substitute participant were imputed for the missing values for the participant of interest.

Variables that could not be imputed and remained empty included, from **Table 1**, Demographics

(e.g. weight, height, finances), MS Disease Characteristics, Environment, and Health Care

Services.

Data Analysis: Data was analyzed using IBM SPSS software v20. Frequencies and descriptive

statistics (mean, SD and data range) were used to determine subject characteristics.

RESULTS

Survey Response

We aimed to recruit 1250 participants for the study and through exhaustive sampling we

contacted 921 (74% of target) people with MS who met inclusion criteria. Seven hundred and

forty three participants returned the survey (**Figure 1**; 80.7% response rate). Survey response by

province is illustrated in **Figure 2**. Of the respondents, 90.4% (n=672) were identified through

provincial MS clinics while the remaining 71 self-identified by responding to newspaper ads and

word of mouth. Forty-five people requested help to complete the survey, and 11 participants

asked that the entire survey be completed by phone due to writing or vision difficulties or both.

Additional content was provided by 709 participants in the open-ended questions at the end of

the survey.

Only 563 of 104,763 cells contained missing data (5.37%). Almost every survey

contained one or two random missing items; in some cases answers to these could be inferred

using deductive reasoning (67/104,763=0.06%). We observed no pattern of missing data other than body weight (which we did not impute). The PMS technique was required for 170 cells (170/94,763=0.16%) and the 'hot deck' technique was required in 14 surveys (324 cells/104,763=0.31%). Cases of consecutive missing data seemed to be mainly due to pages adhering together resulting in questions being overlooked.

Insert Figure 1 about here

Insert Figure 2 about here

Sample Characteristics

Participants ranged in age from 55 to 88 years with a mean age of 64.6 years (±6.2). They described experiencing MS symptoms for 20 to 73 years with a mean duration of 32.9 years (±9.5). The respondents reported that the average time from onset of symptoms to diagnosis by a neurologist was 8.1 years (± 9.4) with a range from 0 to 47 years. The number of women outnumbered men 3.5:1 (**Table 2**).

Sixty percent reported at least one year of post-secondary education, and 90% were either retired or unemployed. About twenty-eight percent of the sample (n=212) reported that they were no longer able to walk and either used a wheelchair or were bedridden. The characteristics of the sample are fully described in **Table 2**.

Respondents were categorized by level of disability based on results of the Barthel Index (**Figure 3**) [18]. We measured activity and participation using the FAI which is divided into household (domestic) activity, leisure activity and outdoor activity **(Figure 4)**. Nearly half

13

(50.6%) of the sample frequently participated in household activities but only 13.5% and 27.9%

reported that they frequently engaged in leisure activities and outdoor activities respectively.

Table 2: Sample Characteristics

Characteristic		N (%)
Years with MS Symptoms	20-29	324 (43.6)
	30-39	245 (33.0)
	40-49	135 (18.2)
	50-59	31 (4.2)
	60 or more	7 (0.9)
Initial MS Diagnosis	Relapsing-Remitting	386 (52.0)
	Primary Progressive	99 (13.3)
	Secondary Progressive	65 (8.7)
	Progressive-Relapsing	16 (2.2)
	Benign	43 (5.8)
	Unknown	126 (17.0)
Living situation	Living in a private home	715 (96.2)
	Living in an assisted living complex	16 (2.2)
	Living in long term care	11 (1.5)
	Home Care	146 (19.7)
	Equipment	200 (26.9)
	Home Modifications	73 (9.8)
Private Insurance (Health/Disability)	Yes	393 (52.9)
	No	350 (47.1)

Insert Figure 3 about here

Insert Figure 4 about here

Older people with MS compared to typical older Canadians

A comparison sample of older people (>55) in Canada was derived from the 2012

Canadian Community Health Survey (CCHS; **Table 3**). CCHS respondents over the age of 55

years primarily lived with their spouse or partner (52.5%), with their spouse or partner and

children (11.3%), or alone (22.7%). Only approximately one percent of this sample were living

14

with their parents. According to data derived from the CCHS, older people with MS from our

survey sample have less post-secondary education and are about 8 times less likely to be

employed full-time. About half of the MS survey sample have major mobility challenges (unable

to walk outdoors, use a wheelchair or are bedridden) compared to only 9% in the CCHS sample.

Older people with MS were more likely to engage in physical activity (69.4%) compared to

typical older Canadians (45.3%). They were also more likely to abstain from alcohol and

smoking.

Table 3: Comparison of Sample Characteristics to Others Aging in Canada

Characteristic		Study sample (%)	CCHS sample (%)
Age	55-64	414 (55.7)	4,671,364.6 (48.9)
	65-74	274 (36.9)	2,891,671.1 (30.3)
	75+	55 (7.4)	1,989,358.6 (20.8)
Gender	Males	166 (22.3)	4,568,522.0 (47.8)
	Females	577 (77.7)	4,983,872.3 (52.2)
Education	Less than high school	74 (10.0)	1,241,946 (15.2)
	High School	222 (29.9)	1,083,618 (13.3)
	1-2 year post-secondary	189 (25.4)	4,088,252 (4.9)
	Complete Post-graduate	258 (34.7)	5,442,586 (66.6)
Employment Status	Retired	504 (67.8)	2,878,200 (46.3)
	Unemployed	166 (22.3)	302,942 (4.8)
	Employed Full-time	30 (4.0)	2,068,571 (33.3)
	Employed Part-time	19 (2.6)	698,125 (11.2)
	Employed Casual	24 (3.2)	266,419 (4.3)
Mobility	Walk independently with or without cane outdoors	351 (47.2)	8,004,425 (90.9)
	Walk with cane or help indoors	180 (24.2)	593,584 (6.7)
	Wheelchair	161 (21.7)	
	Unable to move	51 (6.9)	204,744 (2.3)
Lifestyle	Moderate to Vigorous Exercise	193 (25.9)	1,764,305 (20.7)
	Some physical activity	316 (42.5)	2,083,695 (24.5)
	No physical activity	234 (31.5)	4,652,856 (54.7)
	No alcohol use	385 (51.8)	2,226,486 (26.3)
	14 or less drinks per week	344 (46.3)	1,242,238 (14.6)
	>14 drinks per week	14 (1.9)	5,009,245 (59)
	Non-Smokers	676 (91.0)	7,422,711 (84.4)
	Never smoked	272 (36.6)	
	Quit	404 (54.4)	
	Smokers	67 (9.0)	1,372,885 (15.6)

15

DISCUSSION

The purpose of this national cross-sectional survey was to describe aging with MS in

Canada that would provide the data necessary to determine, in future analysis, the influence of

personal, health and environmental factors on quality of life and disability among older people

with MS. Incidence and prevalence estimates of MS in Canada are amongst the highest

worldwide [36] and a shift in peak age prevalence of MS to older ages suggesting that persons

with MS in Canada are living longer [2]. Interventions to promote successful aging with MS may

take on more importance over the next decade since quality-of-life and productivity in advanced

age is a desired outcome for most [6]. To our knowledge this is the most comprehensive study

focusing on examination of health and lifestyle factors specifically among older persons with

MS.

The prevalence of MS in Canada has been estimated to be 240 per 100,000 [36]. The

CCHS estimates that there are 93,535 Canadians living with MS [33] and since Statistics Canada

estimates that people over 55 make up about 27.7% of the population [37], there could be

approximately 25,000 people with MS over 55 years of age. We attempted to contact as many

older people with MS as possible and our sample (n=743) likely represents about 3% of this

group, less than our initial 5% target. Data quality was very good with only 5.4% missing data

and 709 respondents providing optional qualitative data. The high rates of response and

completion and may be due to pre-screening of potential respondents at clinic sites. Only 7.5%

of respondents required assistance by the research team but we were unable to discern survey

completion by proxy.

With an average age about 65 years, our respondents are 10 to 25 years older than cohorts

examined in previous studies of older people with MS [38-44]. Compared to these previous

studies, which reported the number of years since MS diagnosis ranging from 8-19 years [39 40],

our participants have been diagnosed with MS for 24.8 (±10.0) years. Our respondents' level of

education aligns with most other studies of people with MS [39-41 43] .The group is fairly well-

educated which is not surprising considering characteristics of people who respond to surveys in

general [45]. When compared to the Canadian population [33], fewer of our respondents had

advanced education including post-secondary degrees and post-graduate degrees. Furthermore,

only about 10% of our sample was employed in any capacity which is substantially lower than

other studies of older people with MS [38 40 43]. Since maintaining employment is associated

with better quality-of-life, at least in younger people with MS [43], factors associated with

employment and retirement as one ages with MS will be an important area of future study.

More than a quarter of our cohort were severely disabled (28.6%); over ten times that of

aging counterparts in Canada (2.3%). They either were restricted to ambulation with a

wheelchair or walking with physical assistance indoors or were bedridden; an interesting finding

given that most respondents lived in private residences (96.2%) without home care, equipment or

home modifications. Since only about half of respondents had private health insurance, it is

possible that most people manage at home with few resources outside of the publicly-funded

health system and the care provided by spouses and children. It was interesting that only a small

percentage of survey respondents engaged in leisure or outdoor activity (Figure 4). Since the

proportion of respondents living in assisted-living and long-term care in this study was small, our

sample may not be representative of older people with MS living in these settings.

In terms of lifestyle behaviours, the participants in this study were more physically active

and less likely to drink alcohol or smoke compared to their Canadian counterparts [33]. In large

cohorts of people with MS in the United Kingdom (n=895) and Belgium (n=1372), healthy

17

lifestyle behaviours are associated with less severe and less rapid disability progression [46 47]. Poor lifestyle behaviors, specifically smoking, have been associated with increased risk of comorbid diseases [48] and significantly lower HRQOL when compared to people with MS who have never smoked [49]. Future studies will examine the role of health behaviors and disability in this group of older people with MS.

Although this unique cohort may provide new insights on aging with MS, there are some study limitations. The cross sectional design limits our ability to assess change and the effects of variables on individual outcomes over time. By nature of the volunteer survey design, our sample may be biased in that active participants were more likely to respond. Even though we provided assistance over the phone, those with significant disability who required assistance may have declined. The low sampling of persons in nursing homes and assisted living situations and those older than 75 years highlights the need for specialized recruitment strategies to study this sub-set of people living with MS. Although preliminary testing indicated that participants preferred paper, a web-based version may have improved our recruitment. We also have compared our sample to the Canadian Census CCHS sample. The survey questions do not perfectly align so the values are estimates only. A final limitation of the survey was that we selected the Simple Lifestyle Indicator Questionnaire to assess health behaviours because of its short, simple design, so the data collected lacks detail on diet behaviours which will limit future analysis.

Conclusion

Despite barriers to participation, we were able to recruit and gather detailed responses (with good data quality) from a large proportion of older Canadians with MS. Even with extensive pretesting, national collaboration, exhaustive sampling and high return rates, our

18

recruitment (n=743) was less than our target (n=1250). However, we were able to recruit a large

proportion of people who were severely disabled even though only 7.5% of respondents

requested assistance. The data suggests that this sample of older people with MS are less likely

to be employed, are more disabled but have more positive health behaviours than other older

Canadians.

Contributorship Statement

Concept development and funding applications- MP, JDF, MG

Ethics applications and participant recruitment-MP, OJM, CH, SH, JDF, ADS, PO, SAM, LMM,

PS, NM, RAM, MS

Data collection, management and analysis-MP, OJM, SB, CH, SH, PWA

Manuscript preparation and /or review-MP, OJM, CH, JDF, ADS, PO, SAM, LMM, PS, NM,

RAM, MS, MG

19

Competing Interests

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Data Sharing

 Additional data can be obtained by contacting Dr. Michelle Ploughman at

Michelle.Ploughman@med.mun.ca.

22

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27

Figure Legends:

Figure 1: Survey Respondents

Figure 2: Number of respondents mapped by postal code

Figure 3: Frequency of Barthel Index score categories: A score of 100 on the Barthel Index suggests that an individual is independently ambulatory, can ascend and descend stairs on their own, is continent and able to perform ADLs without help. Fifteen percent of this cohort were independent. A Barthel Index score of 91-99 suggests slight dependence (16%); 61-90 suggests moderate dependence (47%); 21-60 suggests severe dependence (16%) and 0-20 represents complete dependence (7%).

Figure 4: Frequency of Frenchay Activities Index score categories

28

The Canadian Survey of Health, Lifestyle and Aging with Multiple Sclerosis; Methodology and Initial Results

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Key Words: aging; diet; exercise; health behaviours; multiple sclerosis; neurodegenerative disease; older persons; quality of life

Short Title: Health Lifestyle and Aging with Multiple Sclerosis

Tables: 3
Figures: 4

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ABSTRACT

Objective

People with multiple sclerosis (MS) are living longer so strategies to enhance long term health and quality of life are garnering more interest. We aimed to create a profile of aging with MS in Canada by recruiting 1250 (5% of the Canadian population over 55 with MS) participants and focusing data collection on health and lifestyle factors, disability, participation and quality of life in order to determine factors associated with healthy aging.

Design

National multi-centre postal survey

Setting

Recruitment from Canadian MS clinics, MS Society of Canada chapters, and newspaper advertisements

Participants

People aged 55 years or older with MS symptoms more than 20 years

Outcome Measures

Validated outcome measures and custom-designed questions examining MS disease characteristics, living situation, disability, co-morbid conditions, fatigue, health behaviours, mental health, social support, impact of MS, and others.

Results

Of the 921 surveys, 743 were returned (80.7% response rate). Participants (mean age 64.6 ±6.2 years) reported living with MS symptoms for an average of 32.9±9.5 years and 28.6% were either wheelchair users or bedridden. There was only 5.4% missing data and 709 respondents provided optional qualitative information. According to data derived from the 2012 Canadian Community Health Survey of Canadians over 55 years of age, older people with MS from this survey sample are about 8 times less likely to be employed full-time. Older people with MS were less likely to engage in regular physical activity (26.7%) compared to typical older Canadians (45.2%). However, they were more likely to abstain from alcohol and smoking.

Conclusion

Despite barriers to participation, we were able to recruit and gather detailed responses (with good data quality) from a large proportion of older Canadians with MS. The data suggests that this sample of older people with MS are less likely to be employed, are less active and more disabled than other older Canadians.

3

Strengths and limitations of this study

- This unique cohort provides new insights on aging with MS. With an average age about 65 years, our respondents are 10 to 25 years older than cohorts examined in previous studies of older people with MS.

- Our recruitment methods and a very high survey return rate allowed us to obtain data from about 3% of our target population.

- With only about 10% of our sample being employed in any capacity, our results point to a need to understand retirement and employment in aging with MS.

- The cross sectional design limits our ability to assess change and the effects of variables on individual outcomes over time.

- The low sampling of persons in nursing homes and assisted living situations highlights the need for specialized recruitment strategies to study this sub-set of people living with MS.

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INTRODUCTION

Multiple Sclerosis (MS) is a highly unpredictable and heterogeneous autoimmune disease diagnosed between the ages of 18-40 years. Affecting women more than men, the cause of MS is unknown, however research suggests that a combination of environmental factors and genetic predisposition may be the trigger for disease onset [1]. The number of people with MS over the age of 55 is increasing, possibly due to improved longevity and more effective treatments [2]. On the other hand, several authors have shown that smoking [3] and cardiovascular disease [4] accelerate disease progression. People with MS are interested in strategies that minimize disability and enhance role participation and quality of life [5]. The uncertainty surrounding MS progression along with aging MS patients warrants the need for investigation into potential disease modifying health behaviours. Older individuals who have lived with MS for many years may provide insight into factors that contribute to living a long and healthy life with MS [6].

Older people with MS are often excluded from MS research. Studies involving clinical drug trials [7] and exercise interventions [8], in particular, target patients with mild relapsing-remitting disease. Furthermore, because they may not require intensive medical oversight associated with taking disease-modifying drugs, older patients may not attend MS clinics as often as those recently diagnosed. The older MS cohort are also more likely to be disabled and living in an institutional setting, making recruitment challenging. In addition, disability-related impairments such as those affecting vision, cognition and coordination complicate survey and patient-reported outcome administration [9].

5

In order to create a profile of aging with MS in Canada, we developed a national cross-sectional survey, based on previous qualitative research [5 6], using validated patient-reported outcome measures [9]. We focused on health and lifestyle factors, disability, participation and quality of life, targeting people 55 years of age and older with MS symptoms for 20 or more years. By partnering with major MS clinic registries and MS society chapters, we hypothesized that we would be able to reach a representative sample of about 5% of the 'aging with MS in Canada' cohort.

METHODS

Participants and Sampling: We targeted Canadians, aged 55 years or older, who had had self-reported MS symptoms for 20 or more years. Prior to recruitment, the study was approved by 11 health research ethics boards in eight Canadian provinces. Between May 2011 and December 2012, participants were recruited by telephone from lists of eligible MS clinic patients and by public advertising through the MS Society of Canada Research Internet Portal [10], local MS Society chapters and their newsletters, and newspaper advertisements. A confirmed diagnosis from a neurologist was available for participants recruited through the MS clinic databases; self-identified participants provided a diagnosis date and neurologist name to confirm their diagnosis. Rather than calculating a sample size, we used an exhaustive sampling technique to obtain a large and representative sample; for example repeatedly targeting regional newspapers, following-up at study sites, making formal and informal contacts with MS Society Chapter support groups.

After obtaining consent using a standard script, we mailed participants the questionnaire, with an information sheet, a toll-free telephone helpline number and email address and a prepaid

6

reply envelope. We requested that participants return the completed survey in 2 weeks; non-responders were telephoned for follow-up at 4 weeks. Participants who wished to complete the survey by telephone were encouraged to do so. Each questionnaire was coded to maintain anonymity.

Survey Design: The questionnaire consisted of validated patient-reported outcome tools and additional custom-designed questions chosen based on pilot research in a small sample of older people with MS [9]. We determined during this step that participants preferred a paper rather than online version of the survey as well as larger 14-point font, divided into sections that grouped similar questions together. Respondents were instructed to complete the survey in these sections (chapters) taking a break in between. Since we previously observed confusion with questions involving temporal parameters, questions regarding activity involvement that followed the same timeline (e.g. weekly, monthly, or yearly) were placed in sequence. To further examine the acceptability of the survey and to minimize skipped or misunderstood items, we asked the first 14 participants (11 returns) to provide feedback on the content, format and response burden. This feedback was integrated into the final version of the questionnaire but the responses were not included in the final data.

In order to include people with MS in the province of Quebec, Canada, the entire survey including the cover letter was translated into french by one independent professional translator. We also obtained french versions of previously validated tools. Four native french speakers involved in MS research made corrections to the initial translation in sequence. The corrections where then consolidated by a fifth french speaking MS researcher. The advertisement and

7

consent scripts were translated by a native french speaking MS researcher and reviewed and corrected by a second.

Survey Content: The final survey consisted of five chapters (**Table 1**) ending with open response questions for participants to provide additional comments. Where appropriate, we obtained permission from the developers to use previously validated tools.

We used the Multiple Sclerosis Impact Scale (MSIS-29), the Barthel Index and the Co-morbidity Questionnaire to assess health. The MSIS-29 consists of 29 questions: 20 address the physical impact and nine address the psychological impact of MS generating separate or combined scores as a percentage of 100. Higher scores indicate greater impact of MS [11]. The MSIS-29 physical component correlates with the Barthel Index (0.71) and the psychological component with EQ-5D (0.68). It is reported to have good responsiveness with large to moderate effect sizes [12]. The Barthel Index measures function and mobility in activities of daily living (ADL) in ten areas: feeding, bathing, grooming, dressing, bowel control, bladder control, toileting, transfers, ambulation and stair climbing [13]. Items are rated in terms of whether individuals can perform activities independently, with some assistance, or are completely dependent, with a total score ranging from 0 (complete assistance required) to 100 (independent). The Barthel Index has been tested in people with MS [14-16] and is reliable whether administered by telephone, in-person or by mail [17] with effect sizes comparable to the Functional Independence Measure (0.34) [18]. The list of co-morbidities used in this survey was adapted from Marrie and Horwitz [19 20] in consultation with Dr. Marrie (personal communication).

8

We determined the degree of participation in instrumental activities of daily living

(iADL) using the Frenchay Activities Index (FAI) and individual components of lifestyle

(exercise, diet, smoking, alcohol, and stress) using the Simple Lifestyle Indicator Questionnaire

(SLIQ). The FAI assesses the frequency of participation in household chores, social activities,

work and leisure for a summed raw score of 15 to 60; higher score indicating more frequent

participation [21]. The FAI has excellent test-retest reliability as a mailed questionnaire (0.96)

[22] and correlates well with face-to-face interview scores [23]. The FAI has been mainly used in

stroke but has also been used in large MS population studies [24 25]. The SLIQ was developed

to measure the individual components of lifestyle that affect cardiovascular disease [26]. Initial

content and face validity were assessed by the developers among 136 people attending a family

practice clinic[26] and SLIQ scores were highly correlated with those of blinded reviewers

(0.77). We were also interested in mental health, coping and social support in aging with MS.

The Hospital Anxiety and Depression Scale (HADS) is a self-assessment scale found to reliably

screen for depression and anxiety in multiple sclerosis patients [27]. It is divided into an Anxiety

subscale (HADS-A) and a Depression subscale (HADS-D) each containing seven intermingled

items scored out of 21; higher score indicating greater symptoms [28]. A threshold score of 8 or

higher on HADS subscales had high sensitivity (Depression 90%, Anxiety 88.5%) and

specificity (Depression 87.3%, Anxiety 80.7%) compared to structured interview using DSM-1

criteria among people with MS [27]. Resilience, the ability to overcome adversity, was measured

using the 25 item Resilience Scale. Responses to the test questions range from 1 (disagree) to 7

(agree) and the summed score can be further interpreted as, low resilience (<120), moderate

resilience (125-145), and high resilience (>145) [29] and has been validated in older community-

9

living individuals with high internal consistency reliability (0.91)[29] . The Personal Resource

Questionnaire (PRQ-2000) measures social support and consists of 15 statements with which the

subject agrees or disagrees based on a seven-point Likert scale; higher scores indicating higher

support (e.g. I belong to a group in which I feel important 1-Strongly Disagree to 7-Strongly

Agree). PRQ-2000 demonstrates good internal consistency (0.87 to 0.93), adequate construct

validity (moderate correlations with anxiety -0.37, neuroticism -0.28 and extroversion 0.32) and

good predictive and construct validity in multiple chronic disease data sets [30]. Mailed versions

have been used in community-living women with chronic health conditions [31] and adults with

MS [32].

Table 1: Survey Content

CHAPTER	DOMAINS	MEASUREMENT TOOLS
You and Your MS (5 pages)	**Demographics**	Postal code, gender, height, weight, age, finances and education
	MS Disease Characteristics	Symptom onset, time since diagnosis, and type of MS
	Environment	Living situation, accessibility and home modifications
Your Health (6 pages)	**Health-Related Quality of Life**	Visual analogue scale of perceived health status [9] Multiple Sclerosis Impact Scale-29 [11]
	Physical Health and Disability	Barthel Index [12] Co-Morbidity Questionnaire [17]
	Health Care Services	Use and satisfaction with health care services, medications and complementary/alternative health.
Your Activities (7 pages)	**Participation and instrumental Activities of Daily Living**	Frenchay Activities index [19]; Employment and impact of fatigue
	Lifestyle	Simple Lifestyle Indicator Questionnaire (diet, exercise, stress, smoking, alcohol) [24]
Your Thoughts and Feelings (8 pages)	**Mental/ Cognitive Health**	Hospital Anxiety and Depression Scale (HADS) Resilience Scale [25] Problems with concentration and memory
Your Social Life (4 pages)	**Social Support**	Personal Resource Questionnaire-2000 [30]

10

Canadian comparison data: Comparative data was collected from the Canadian Community Health Survey (CCHS) 2012 version; a national cross-sectional survey that gathers information about health, social and economic status and lifestyle behaviours of the population. Data was extracted from the CCHS database using the University of Toronto Data Library Service (DLS) [33]. A CCHS sample was selected based on age (>55 years). Data was collected from CCHS questions that matched question from our survey (e.g. mobility from the Barthel Index and lifestyle from the SLIQ). Outputs (ie. highest level of education, employment status) were analyzed using Survey Documentation & Analysis (SDA) software [34]. Frequency tables were created for variables of interest.

Data Cleaning and Imputation: We custom designed the database application to house project data and minimize error during data imputation. Missing data was imputed using three techniques: (1) deductive imputation, (2) person mean substitution, and (3) 'hot deck' imputation [35]. The deductive technique was used to impute missing data when there was sufficient comments and answers to related questions. If less than half of the data was missing on a section, scale, or subscale, person mean substitution (PMS) was used. PMS takes the mean score of the particular participant on that section, scale, or subscale and uses the mean as the value for the missing data. If greater than half of the data was missing on a section, scale, or subscale, 'hot deck' imputation was used [35]. This involved taking a value from the "hot deck" or in other terms, finding another participant of the same gender, age (±5 years), education level, and living in the same province. Hot deck imputation was selected for this study because it is proven to be the most efficient method of data imputation as it is more robust in large samples when

11

compared to other imputation methods [35]. The exact scores for each question from the

substitute participant were imputed for the missing values for the participant of interest.

Variables that could not be imputed and remained empty included, from **Table 1**, Demographics

(e.g. weight, height, finances), MS Disease Characteristics, Environment, and Health Care

Services.

Data Analysis: Data was analyzed using IBM SPSS software v20. Frequencies and descriptive

statistics (mean, SD and data range) were used to determine subject characteristics.

RESULTS

Survey Response

We aimed to recruit 1250 participants for the study and through exhaustive sampling we

contacted 921 (74% of target) people with MS who met inclusion criteria. Seven hundred and

forty three participants returned the survey (**Figure 1**; 80.7% response rate). Survey response by

province is illustrated in **Figure 2**. Of the respondents, 90.4% (n=672) were identified through

provincial MS clinics while the remaining 71 self-identified by responding to newspaper ads and

word of mouth. Forty-five people requested help to complete the survey, and 11 participants

asked that the entire survey be completed by phone due to writing or vision difficulties or both.

Additional content was provided by 709 participants in the open-ended questions at the end of

the survey.

Only 563 of 104,763 cells contained missing data (5.37%). Almost every survey

contained one or two random missing items; in some cases answers to these could be inferred

12

using deductive reasoning (67/104,763=0.06%). We observed no pattern of missing data other than body weight (which we did not impute). The PMS technique was required for 170 cells (170/94,763=0.16%) and the 'hot deck' technique was required in 14 surveys (324 cells/104,763=0.31%). Cases of consecutive missing data seemed to be mainly due to pages adhering together resulting in questions being overlooked.

Insert Figure 1 about here

Insert Figure 2 about here

Sample Characteristics

Participants ranged in age from 55 to 88 years with a mean age of 64.6 years (±6.2). They described experiencing MS symptoms for 20 to 73 years with a mean duration of 32.9 years (±9.5). The respondents reported that the average time from onset of symptoms to diagnosis by a neurologist was 8.1 years (± 9.4) with a range from 0 to 47 years. The number of women outnumbered men 3.5:1 (**Table 2**).

Sixty percent reported at least one year of post-secondary education, and 90% were either retired or unemployed. About twenty-eight percent of the sample (n=212) reported that they were no longer able to walk and either used a wheelchair or were bedridden. The characteristics of the sample are fully described in **Table 2**.

Respondents were categorized by level of disability based on results of the Barthel Index (**Figure 3**) [18]. We measured activity and participation using the FAI which is divided into household (domestic) activity, leisure activity and outdoor activity **(Figure 4)**. Nearly half

Table 2: Sample Characteristics

Characteristic		N (%)
Years with MS Symptoms	20-29	324 (43.6)
	30-39	245 (33.0)
	40-49	135 (18.2)
	50-59	31 (4.2)
	60 or more	7 (0.9)
Initial MS Diagnosis	Relapsing-Remitting	386 (52.0)
	Primary Progressive	99 (13.3)
	Secondary Progressive	65 (8.7)
	Progressive-Relapsing	16 (2.2)
	Benign	43 (5.8)
	Unknown	126 (17.0)
Living situation	Living in a private home	715 (96.2)
	Living in an assisted living complex	16 (2.2)
	Living in long term care	11 (1.5)
	Home Care	146 (19.7)
	Equipment	200 (26.9)
	Home Modifications	73 (9.8)
Private Insurance (Health/Disability)	Yes	393 (52.9)
	No	350 (47.1)

Insert Figure 3 about here

Insert Figure 4 about here

Older people with MS compared to typical older Canadians

14

with their parents. According to data derived from the CCHS, older people with MS from our

survey sample have less post-secondary education and are about 8 times less likely to be

employed full-time. About half of the MS survey sample have major mobility challenges (unable

to walk outdoors, use a wheelchair or are bedridden) compared to only 9% in the CCHS sample.

Older people with MS were more likely to engage in physical activity (69.4%) compared to

typical older Canadians (45.3%). They were also more likely to abstain from alcohol and

smoking.

Table 3: Comparison of Sample Characteristics to Others Aging in Canada

Characteristic		Study sample (%)	CCHS sample (%)
Age	55-64	414 (55.7)	4,671,364.6 (48.9)
	65-74	274 (36.9)	2,891,671.1 (30.3)
	75+	55 (7.4)	1,989,358.6 (20.8)
Gender	Males	166 (22.3)	4,568,522.0 (47.8)
	Females	577 (77.7)	4,983,872.3 (52.2)
Education	Less than high school	74 (10.0)	1,241,946 (15.2)
	High School	222 (29.9)	1,083,618 (13.3)
	1-2 year post-secondary	189 (25.4)	4,088,252 (4.9)
	Complete Post-graduate	258 (34.7)	5,442,586 (66.6)
Employment Status	Retired	504 (67.8)	2,878,200 (46.3)
	Unemployed	166 (22.3)	302,942 (4.8)
	Employed Full-time	30 (4.0)	2,068,571 (33.3)
	Employed Part-time	19 (2.6)	698,125 (11.2)
	Employed Casual	24 (3.2)	266,419 (4.3)
Mobility	Walk independently with or without cane outdoors	351 (47.2)	8,004,425 (90.9)
	Walk with cane or help indoors	180 (24.2)	593,584 (6.7)
	Wheelchair	161 (21.7)	
	Unable to move	51 (6.9)	204,744 (2.3)
Lifestyle	Moderate to Vigorous Exercise	193 (25.9)	1,764,305 (20.7)
	Some physical activity	316 (42.5)	2,083,695 (24.5)
	No physical activity	234 (31.5)	4,652,856 (54.7)
	No alcohol use	385 (51.8)	2,226,486 (26.3)
	14 or less drinks per week	344 (46.3)	1,242,238 (14.6)
	>14 drinks per week	14 (1.9)	5,009,245 (59)
	Non-Smokers	676 (91.0)	7,422,711 (84.4)
	Never smoked	272 (36.6)	
	Quit	404 (54.4)	
	Smokers	67 (9.0)	1,372,885 (15.6)

15

DISCUSSION

The purpose of this national cross-sectional survey was to describe aging with MS in Canada that would provide the data necessary to determine, in future analysis, the influence of personal, health and environmental factors on quality of life and disability among older people with MS. Incidence and prevalence estimates of MS in Canada are amongst the highest worldwide [36] and a shift in peak age prevalence of MS to older ages suggesting that persons with MS in Canada are living longer [2]. Interventions to promote successful aging with MS may take on more importance over the next decade since quality-of-life and productivity in advanced age is a desired outcome for most [6]. To our knowledge this is the most comprehensive study focusing on examination of health and lifestyle factors specifically among older persons with MS.

The prevalence of MS in Canada has been estimated to be 240 per 100,000 [36]. The CCHS estimates that there are 93,535 Canadians living with MS [33] and since Statistics Canada estimates that people over 55 make up about 27.7% of the population [37], there could be approximately 25,000 people with MS over 55 years of age. We attempted to contact as many older people with MS as possible and our sample (n=743) likely represents about 3% of this group, less than our initial 5% target. Data quality was very good with only 5.4% missing data and 709 respondents providing optional qualitative data. The high rates of response and completion and may be due to pre-screening of potential respondents at clinic sites. Only 7.5% of respondents required assistance by the research team but we were unable to discern survey completion by proxy.

With an average age about 65 years, our respondents are 10 to 25 years older than cohorts examined in previous studies of older people with MS [38-44]. Compared to these previous

16

studies, which reported the number of years since MS diagnosis ranging from 8-19 years [39 40], our participants have been diagnosed with MS for 24.8 (±10.0) years. Our respondents' level of education aligns with most other studies of people with MS [39-41 43] .The group is fairly well-educated which is not surprising considering characteristics of people who respond to surveys in general [45]. When compared to the Canadian population [33], fewer of our respondents had advanced education including post-secondary degrees and post-graduate degrees. Furthermore, only about 10% of our sample was employed in any capacity which is substantially lower than other studies of older people with MS [38 40 43]. Since maintaining employment is associated with better quality-of-life, at least in younger people with MS [43], factors associated with employment and retirement as one ages with MS will be an important area of future study.

More than a quarter of our cohort were severely disabled (28.6%); over ten times that of aging counterparts in Canada (2.3%). They either were restricted to ambulation with a wheelchair or walking with physical assistance indoors or were bedridden; an interesting finding given that most respondents lived in private residences (96.2%) without home care, equipment or home modifications. Since only about half of respondents had private health insurance, it is possible that most people manage at home with few resources outside of the publicly-funded health system and the care provided by spouses and children. It was interesting that only a small percentage of survey respondents engaged in leisure or outdoor activity (Figure 4). Since the proportion of respondents living in assisted-living and long-term care in this study was small, our sample may not be representative of older people with MS living in these settings.

In terms of lifestyle behaviours, the participants in this study were more physically active and less likely to drink alcohol or smoke compared to their Canadian counterparts [33]. In large cohorts of people with MS in the United Kingdom (n=895) and Belgium (n=1372), healthy

17

lifestyle behaviours are associated with less severe and less rapid disability progression [46 47]. Poor lifestyle behaviors, specifically smoking, have been associated with increased risk of comorbid diseases [48] <mark>and significantly lower HRQOL when compared to people with MS who have never smoked [49].</mark> Future studies will examine the role of health behaviors and disability in this group of older people with MS.

Although this unique cohort may provide new insights on aging with MS, there are some study limitations. The cross sectional design limits our ability to assess change and the effects of variables on individual outcomes over time. By nature of the volunteer survey design, our sample may be biased in that active participants were more likely to respond. Even though we provided assistance over the phone, those with significant disability who required assistance may have declined. The low sampling of persons in nursing homes and assisted living situations and those older than 75 years highlights the need for specialized recruitment strategies to study this sub-set of people living with MS. <mark>Although preliminary testing indicated that participants preferred paper, a web-based version may have improved our recruitment. We also have compared our sample to the Canadian Census CCHS sample. The survey questions do not perfectly align so the values are estimates only. A final limitation of the survey was that we selected the Simple Lifestyle Indicator Questionnaire to assess health behaviours because of its short, simple design, so the data collected lacks detail on diet behaviours which will limit future analysis.</mark>

Conclusion

Despite barriers to participation, we were able to recruit and gather detailed responses (with good data quality) from a large proportion of older Canadians with MS. Even with extensive pretesting, national collaboration, exhaustive sampling and high return rates, our

18

recruitment (n=743) was less than our target (n=1250). However, we were able to recruit a large proportion of people who were severely disabled even though only 7.5% of respondents requested assistance. The data suggests that this sample of older people with MS are less likely to be employed, are more disabled but have more positive health behaviours than other older Canadians.

Contributorship Statement

Concept development and funding applications- MP, JDF, MG

Ethics applications and participant recruitment-MP, OJM, CH, SH, JDF, ADS, PO, SAM, LMM, PS, NM, RAM, MS

Data collection, management and analysis-MP, OJM, SB, CH, SH, PWA

Manuscript preparation and /or review-MP, OJM, CH, JDF, ADS, PO, SAM, LMM, PS, NM, RAM, MS, MG

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Data Sharing

Additional data can be obtained by contacting Dr. Michelle Ploughman at Michelle.Ploughman@med.mun.ca.

22

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944 potential participants contacted based on initial consent and eligibility

11 ineligible (age, years with MS)
1 in hospital
16 declined

916 surveys sent

143 required follow up
    113 were unable to be contacted
    7 declined
    1 died
    22 were sent new surveys
71 returned surveys after follow up

743 surveys returned
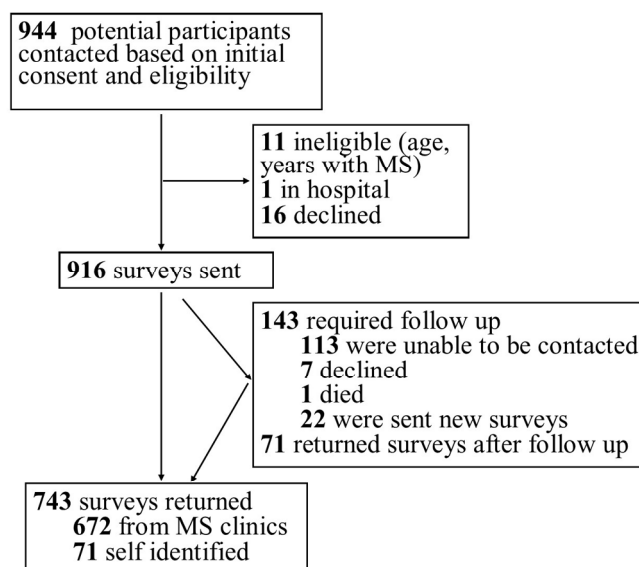   **672** from MS clinics
    71 self identified

Figure 1: Survey Respondents
161x152mm (300 x 300 DPI)

Figure 2: Number of respondents mapped by postal code
26x15mm (300 x 300 DPI)
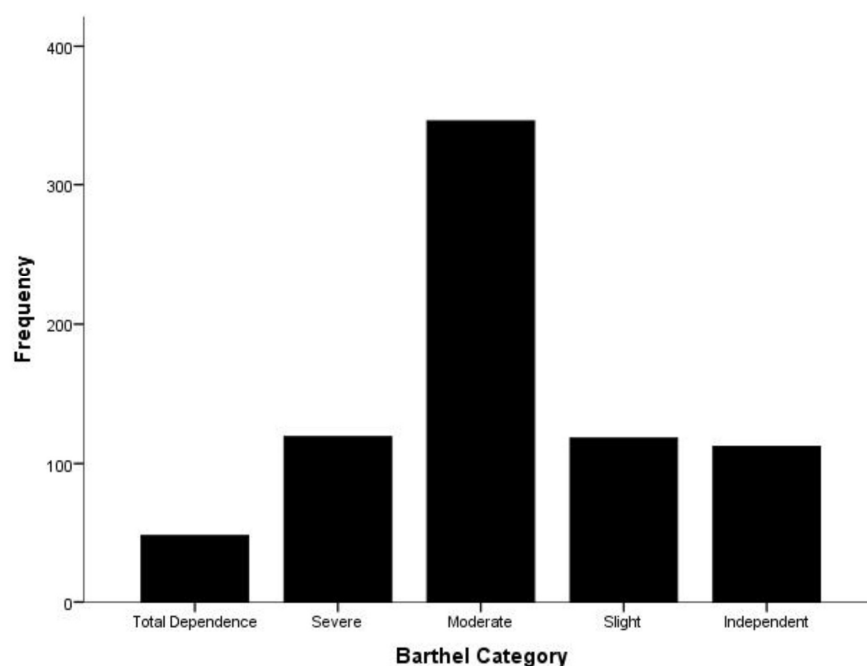
Figure 3: Frequency of Barthel Index score categories: A score of 100 on the Barthel Index suggests that an individual is independently ambulatory, can ascend and descend stairs on their own, is continent and able to perform ADLs without help. Fifteen percent of this cohort were independent. A Barthel Index score of 91-99 suggests slight dependence (16%); 61-90 suggests moderate dependence (47%); 21-60 suggests severe dependence (16%) and 0-20 represents complete dependence (7%).

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Figure 4: Frequency of Frenchay Activities Index score categories
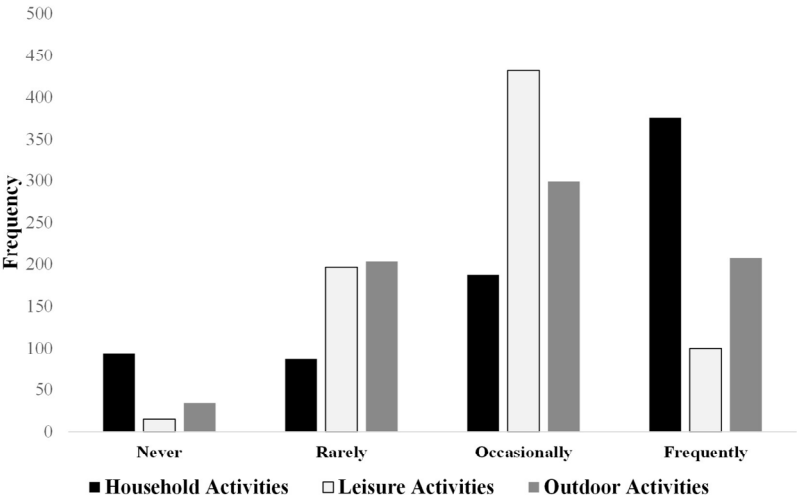174x139mm (300 x 300 DPI)

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Complete
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	✓
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	✓
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	✓
Objectives	3	State specific objectives, including any prespecified hypotheses	✓
Methods			
Study design	4	Present key elements of study design early in the paper	✓
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	✓
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	✓
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	✓
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	✓
Bias	9	Describe any efforts to address potential sources of bias	✓
Study size	10	Explain how the study size was arrived at	✓
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	✓
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	✓
		(*b*) Describe any methods used to examine subgroups and interactions	✓
		(*c*) Explain how missing data were addressed	✓
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	✓
		(*e*) Describe any sensitivity analyses	✓

Results

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	✓
		(b) Give reasons for non-participation at each stage	✓
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	✓
		(b) Indicate number of participants with missing data for each variable of interest	✓
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	✓
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	✓
		(*b*) Report category boundaries when continuous variables were categorized	✓
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	✓
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	✓

Discussion

Key results	18	Summarise key results with reference to study objectives	✓
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	✓
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	✓
Generalisability	21	Discuss the generalisability (external validity) of the study results	✓

Other information

Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	✓

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.